

“Promoting Consumer Direction in Aging Services”

Selected Resources on Consumer Direction

Promoting Consumer Direction in Aging Services is a joint project of the National Association of State Units on Aging (NASUA) and the National Council on the Aging (NCOA) and is funded by The Robert Wood Johnson Foundation.

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As part of the project, NASUA is developing a comprehensive resource compendium of literature, resources materials, and web-based information on consumer direction. **The following is an excerpt from that document.**

Section I: “Promoting Consumer Direction in Aging Services” Products

◇ ***The Consumer Direction Tool.*** Developed collaboratively by the National Association of State Units on Aging (NASUA) and the Home and Community Based Services (HCBS) Resource network.

Summary: This self-assessment tool is designed to assist consumers and policy makers determine the extent to which state home and community based service (HCBS) programs offer consumers opportunities to direct their own services. The toolkit included: an introduction describing four goals of the Americans with Disabilities Act (ADA), and the differences between consumer choice and consumer direction; the Tool itself, which has four sections organized around the principles of the ADA (opportunity, meaningful participation, independence, and financial security and other safeguards) with questions in each section designed to give users an idea of how well the state is performing in each of those areas; the discussion guide which provides instructions for completing the Tool; fact sheets which serve as a companion to each section of the Tool and identify factors that may hinder consumer choice and control; and the glossary which defines important terms that are used in the tool.

Availability: This product is available from the “Promoting Consumer Direction in Aging Services” project web site at: www.consumerdirection.org

◇ ***Consumer Choice News.*** Publication of the National Association of State Units on Aging and the National Council on the Aging and supported by the Robert Wood Johnson Foundation.

Summary: This e-newsletter provides updates on national, state, and local programs and policies on consumer-directed services with a focus on older adults. To date, six issues have been published and explore topics ranging from consumer direction in caregiver support programs, ensuring quality, and showcasing the activities of the states participating in the NASUA/NCOA project.

➤ Issue #1: July 2002 – Overview of the NASUA/NCOA project

- Issue #2: October 2002 – State Partnerships and Consumer Direction Self- Assessments
- Issue #3: January 2003 – Quality in HCBS Programs
- Issue #4: June 2003 – Consumer Direction and Family Caregiving
- Issue #5: October 2003 – Consumer Direction and Older Americans Act Programs
- Issue #6: January 2004 – Aging and Disability Resource Centers

Availability: Electronic versions of *Consumer Choice News* may be downloaded at the project’s web site www.consumerdirection.org.

♦*The Myths and Realities of Consumer-Directed Services for Older Persons.* Marie R. Squillace, Ph.D. & James Firman, Ed.D.

Summary: This publication, developed by the National Council on the Aging (NCOA) under the project “*Promoting Consumer Direction in Aging Services*”, synthesizes findings from the research of consumer choice and consumer direction in home and community based services for older persons. Twelve myths about consumer-directed services for older persons are highlighted along with the research and practice-based realities of services delivered in this manner.

Availability: This document is available in PDF and HTML formats:

PDF Version: http://www.consumerdirection.org/pdf/myths_and_realities.pdf

HTML Version: http://www.consumerdirection.org/reso_mandr.php

♦*“Promoting Consumer Direction in Aging Services – Issue Briefs”* Developed by NASUA and NCOA with funding from The Robert Wood Johnson Foundation.

Summary: These issue briefs explore a variety of topics associated with consumer directed services. Issue brief topics include:

- Issue Brief #1: *Promoting Consumer Direction in Aging Services: State Profiles 2002*
- Issue Brief #2: *Consumer Direction: What Does it Mean?*
- Issue Brief #3: *Federal Policy Initiatives and Opportunities in Consumer Direction*
- Issue Brief #4: *Getting Ready for the Coming Challenges and Opportunities in Consumer-Directed Services*
- Issue Brief #5: *Promoting Consumer Direction in Aging Services: State Profiles 2003*

Availability: These documents are available from NASUA, 202-898-2578

◇ ***Project Overview: “Promoting Consumer Direction in Aging Services”*** A joint project of the National Association of State Units on Aging (NASUA) and the National Council on the Aging (NCOA) with funding from The Robert Wood Johnson Foundation (RWJ).

Summary: This document provides an overview of NASUA and NCOA’s joint effort to increase opportunities for consumer direction in home and community based services (HCBS). Building on work done in the “Independent Choices Program”, also funded by RWJ, this three-year project is working with a total of 13 states to develop consumer and policymaker partnerships to assess the HCBS system and develop and implement a consumer direction reform agenda.

Availability: This document is available from NASUA, 1201 15th Street, NW, Suite 350, Washington, DC, 20005. Phone: 202-898-2578.

◇ ***“Promoting Consumer Direction in Aging Services” State Profiles 2002 & 2003*** (Issue Briefs #1 & #5). Compiled by NASUA.

Summary: These documents provide a snapshot of the states participating in the NASUA/NCOA Project and include information about programs and funding sources being assessed and the partnerships that have been developed to assess consumer direction. Contact information for the individuals leading the effort in each state is also provided.

Availability: This document is available from NASUA, 1201 15th Street, NW, Suite 350, Washington, DC, 20005. Phone: 202-898-2578

Section II: Cash & Counseling

◇ ***The Cash and Counseling Demonstration: An Experiment in Consumer-Directed Personal Assistance Services.*** Pamela Doty, Ph.D. U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, 1998.

Summary: This article provides history and background relevant to the Cash and Counseling Demonstration and Evaluation (CCDE) project offering consumers with disabilities the option of a cash allowance and information services program.

Availability: This publication may be downloaded from the ASPE web site at: <http://aspe.hhs.gov/daltcp/reports-c.shtml#Doty14>

◇ ***Early Lessons from the Cash and Counseling Demonstration and Evaluation.*** Kevin J. Mahoney, K. Simone, and L. Simon-Rusinowitz. *Generations*, pp. 41-46, Fall 2000.

Summary: This article describes the implementation, program design, and initial lessons and questions from the Cash and Counseling Demonstration and Evaluation (CCDE) program.

Availability: Single copies and back issues of Generations are available by contacting the American Society on Aging at 415-974-9617.

- ◇ ***Improving the Quality of Medicaid Personal Assistance Through Consumer Direction***
Leslie Foster, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson. Health Affairs: The Policy Journal of the Health Sphere. March 26, 2003.

Summary: This paper presents findings from the cash and counseling program implemented in Arkansas. The survey of 1,739 elderly and non-elderly adults showed that relative to agency-directed services, Cash and Counseling greatly improved satisfaction and reduced most unmet needs. Moreover, contrary to some concerns, it did not adversely affect participants' health and safety.

Availability: This article may be downloaded at:
<http://content.healthaffairs.org/cgi/reprint/hlthaff.w3.162v1.pdf>

- ◇ ***Independent Choices: A publication of the Arkansas Cash & Counseling Demonstration Program.***

Summary: This document provides a description of how Arkansas offered disabled and elderly Medicaid clients in the state a cash allowance to purchase their own services. A discussion of the Arkansas program is provided along with anecdotal reports on some of the program's participants.

Availability: This document is available from the Division of Aging and Adult Services, Arkansas Department of Human Services, 501-682-2441.

- ◇ ***The Effects of Cash and Counseling on Personal Care Services and Medicaid Costs in Arkansas.*** Stacy Dale, Randall Brow, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson. *Health Affairs*. November 2003.

Summary: This document reports on the data collected from survey and Medicaid claims data on 2,008 applicants randomly assigned to treatment or control groups in the Cash and Counseling demonstration program in Arkansas. Findings show the increased receipt of paid care and a reduction in unpaid care.

Availability: This article may be downloaded at:
<http://content.healthaffairs.org/cgi/reprint/hlthaff.w3.566v1.pdf>

- ◇ ***Lessons from the Implementation of Cash and Counseling in Arkansas, Florida and New Jersey.*** Barbara Phillips, Kevin Mahoney, Lori Simon-Rusinowitz, Jennifer Schore, Sandra Barrett, William Ditto, Tom Reimers, and Pamela Doty. Princeton, NJ: Mathematica Policy Research Inc. June 2003

Summary: This article discusses the lessons learned by Arkansas, Florida, and New Jersey in implementing the Cash and Counseling program. Issues discussed include outreach and enrollment, use of consumer representatives, development of allowance spending plans and permitted purchases with the allowance, role of counselors and fiscal agents, the prevention of exploitation and abuse, and program costs.

Availability: This article may be downloaded at:
www.mathematica-mpr.com/publications

Section III: Quality

◇*Blueprint For Quality in Consumer Directed Programs*

By R. Applebaum & S. Kunkel

Summary: This short paper summarizes the findings of interviews with state administrators of consumer-directed programs and face-to-face meetings with consumers, family members, workers, program staff and administrators about their definitions of quality and how quality is currently measured in consumer-directed programs. The conclusion reached is that quality in consumer-directed programs happens because of consumer choice and control over the services they receive.

Availability: This paper may be downloaded at:
http://www.communitylivingta.info/files/5/220/Kunkel_Applebaum.rtf

◇*Making Good Better: Approaches to Evaluating the Quality of Programs and Services.*

By Robert Applebaum, Ph.D. Center for Medicare Education Issue Brief, Vol. 2 (8), 2001.

Summary: This paper explores some of the major questions around the issue of evaluating the quality of programs and services. Questions addressed in this article include: Why worry about quality? What do program evaluation and quality assurance include? What has to happen to achieve quality?

Availability: This report may be downloaded at: www.medicareEd.org

◇*The Quality of Consumer-Directed Long-Term Care.* By Scott Miyake Geron, Ph.D. *Generations*, Fall 2000.

Summary: This article explores some of the differences in how consumers, professionals and caregivers define quality. A series of “Quality Assurance Steps” is outlined and discussed.

Availability: Single copies and back issues of *Generations* are available by contacting the American Society on Aging at 415-974-9617.

◇ ***The Home Care Satisfaction Measure: A Client-Centered Approach to Assessing the Satisfaction of Frail Older Adults with Home Care Services.*** By Scott Miyake Geron, Ph.D., Kevin Smith, Sharon Tennstedt, Alan Jette, Deborah Chassler, and Linda Kasten. Journal of Gerontology: Social Sciences, 52B(5):5259-70. 2000.

Summary: This research paper describes the development of the Home Care Satisfaction Measure (HCSM) which provides a standardized scale of home care satisfaction that is brief, easy to administer and meets standard psychometric criteria for validity and reliability. This HCSM is being used by a number of SUAs and AAAs nationwide to evaluate the quality of in-home supports provided with OAA funds.

Availability: This article is available at a cost of \$5.00 from The Gerontological Society of America, Attn: Melanie Radkiewics, 1030 15th Street, NW, Suite 250, Washington, DC, 20005 or by email at: tkluss@geron.org.

◇ ***Home Care Satisfaction Measure (HCSM).***

Summary: The HCSM is being used by a number of SUAs and AAAs nationwide to evaluate the quality of in-home supports provided with OAA funds.

Availability: The HCSM instrument may be downloaded from the web site of the Performance Outcome Measures Project (POMP) at: www.gpra.net

◇ ***Quality Framework.*** The Centers for Medicare and Medicaid Services (CMS) 2003

Summary: The framework identifies seven quality focus areas for Medicaid waiver home and community based services (HCBS):

- Participant access
- Participant-centered service planning and delivery
- Provider capacity and capabilities
- Participant safeguards
- Participant rights and responsibilities
- Participant outcomes and satisfaction
- System performance

The Home and Community-Based Services (HCBS) Quality Framework is intended to serve as a common frame of reference in support of productive dialogue among all parties who have a stake in the quality of services and supports for people with disabilities. The framework was developed by the Center for Medicaid and State Operations (CMSO) at CMS in partnership with MEDSTAT, the National Association of State Directors of Developmental Disability Services, the National Association of State Units on Aging, the National Association of State Medicaid Directors and the Human Services Research Institute.

Availability: A PDF version of the Framework is available on the CMS website at www.cms.gov or <http://www.cms.hhs.gov/medicaid/waivers/82902ltr.pdf>

◇ ***Promising Practices in Home and Community Based Services.*** The Centers for Medicare and Medicaid Services (CMS)

Summary: The Centers for Medicare and Medicaid Services is sponsoring the development of promising practice reports on home and community based services to assist states, in partnership with their disability and aging communities, to strengthen their community long term support systems. Current topic areas include: access, caregiver support, housing, quality, and self-directed services.

Availability: These reports may be downloaded at:
<http://www.cms.hhs.gov/promisingpractices/default.asp>

◇ ***Personal Assistance for People with Physical Disabilities: Consumer-Direction and Satisfaction with Services.*** Philip W. Beatty, Gordon W. Richmond, Sherri Tepper, and Gerben DeJong. *Archives of Physical Medicine and Rehabilitation*, Vol. 79, pp. 674-677, 1998.

Summary: This report highlights the results of a survey of long-term outcomes among people receiving consumer-directed personal assistance services (PAS) in Virginia and persons on the waiting list to receive those services. Surveys were conducted by mail and telephone. The report concludes that consumer-directed PAS are associated with high levels of satisfaction.

Availability: The abstract and ordering information for this article are available at the web site of the *Archives of Physical Medicine and Rehabilitation*:
www.archives-pmr.org/

◇ ***Consumer Choice News: "Quality in HCBS Programs".*** Issue #3, January 2003. A publication of NASUA and NCOA's project "Promoting Consumer Direction in Aging Services", supported by The Robert Wood Johnson Foundation.

Summary: This issue of Consumer Choice News provides an overview of current initiatives seeking to understand, measure and provide frameworks for quality in home and community based services, particularly consumer-directed programs.

Availability: This document may be downloaded at:
www.consumerdirection.org

◇ *Balancing Safety and Freedom in Consumer-Directed Systems of Support* (June 2001) and *Balancing Safety and Freedom in Consumer-Directed Systems of Support: Strategies and Recommendations* (2003). Charles Moseley, Ed.D., Institute on Disability, University of New Hampshire, June 2001.

Summary: These papers identify and review key issues involved in states' efforts to balance the need to ensure health and safety with the competing necessity to respect the right of the individual to freely determine the events of his or her life. *Strategies and Recommendations* provides concrete strategies and recommendations to address key issues that are present in consumer-directed systems of support.

Availability: Acrobat: http://www.hcbs.org/files/7/328/QI_Final.pdf
RTF: http://www.hcbs.org/files/7/329/QI_Final.rtf

Acrobat: <http://www.hcbs.org/files/7/330/Strategies.pdf>
RTF: <http://www.hcbs.org/files/7/331/Strategies.rtf>

Section IV: Consumer Supports

◇ *Caregivers and Personal Assistants: How to Find, Hire and Manage the People Who Help You (or Your Loved One!)*. Alfred H. DeGraff, M.A., S.E.A. Saratoga Access Publications, Inc., 2002.

Summary: A comprehensive guide for care receivers and caregivers that provides step-by-step strategies for recruiting, interviewing, screening, hiring, training, managing and firing paid providers.

Availability: An "e-book" download is available at www.saratoga-publications.com. This book is available at bookstores or by calling 1-800-266-5564.

◇ *Family Caregivers and Consumer Choice: Options for In-Home Respite Care*. Lynn Friss-Feinberg and Carol J. Whitlatch, Family Caregiver Alliance, San Francisco, CA, August 1997.

Summary: This report on a study of family caregivers served by California's Caregiver Resource Centers includes findings that demonstrate caregivers' valuing safety and reliability over cost and amount of service, caregiver preference for consumer direction, the importance of having choices, lower costs of consumer-directed respite care versus agency respite, and the direct pay model's adaptability.

Availability: This publication may be ordered from the web site of the Family Caregiver Alliance: www.caregiver.org/caregiver

◇*Managing Personal Assistants: A Consumer Guide*, Paralyzed Veterans of America, 2000.

Summary: This guide contains general advice for individuals seeking personal assistance in their homes. The guide provides information on recruiting, hiring, training, keeping and firing personal assistants, funding sources and tax issues; and includes sample forms.

Availability: This publication may be ordered from the Paralyzed Veterans of America's (PVA) Publications Department, 888-860-7244, or PVA's web site: www.pva.org

◇*You Can Do It! A Consumer Guide for Managing Your Own Cash Grant for Household Employees*. John Agosta, Human Services Research Institute. Personal Preference Cash and Counseling Demonstration Program, New Jersey Department of Human Services, 1999.

Summary: A guide intended for consumers participating in the New Jersey Personal Preference Cash and Counseling Program to provide them with information on managing their cash grants without the assistance of a fiscal intermediary.

Availability: This publication may be ordered from the New Jersey Cash & Counseling Demonstration Program, State Office on Disability Services, New Jersey Department of Human Services, PO Box 700, Trenton, NJ 08625-0700, (609) 292-7800 or 1-888 285-3036. The guide may also be downloaded at: <http://www.hhp.umd.edu/AGING/CCDemo/ccbook/index.html>

Section V: Fiscal Agents

◇*Consumer Directed Personal Assistance Services: Key Operational Issues for State CD-PAS Programs Using Intermediary Services Organizations* (Report and Appendices). Susan Flanagan and Pamela Green, The MEDSTAT Group, Cambridge MA, 1997.

Summary: This study examined 23 consumer-directed personal assistance services (CD-PAS) programs in 11 states, focusing on their use of intermediary services organizations (ISOs – also called fiscal agents). It will help states to make decisions about and customize the fiscal management aspects of their consumer-directed programs. The study may also enhance consumers' and advocates' understanding of ISOs and help them engage in constructive discussions with policymakers about the operation and implementation of consumer-directed programs.

Availability: An executive summary of this document may be downloaded at: <http://aspe.hhs.gov/daltcp/reports/cdpases.htm>

◇ ***Consumer Directed Attendant Services: How States Address Tax, Legal and Quality Assurance Issues.*** Sue Flanagan. Department of Health and Human Services (HHS), Office of the Assistant Secretary for Planning and Evaluation (ASPE) Division of Aging and Long-Term Care Policy (DALTCP). April 28, 1994.

Summary: This paper reports the findings of a ten-state study which examined the payment, employer-related tax, legal liability and quality assurance issues related to consumer-directed care attendant (CDCA) programs.

Availability: An abstract of this document may be downloaded at:
<http://aspe.hhs.gov/daltcp/reports-c.shtml#Flanagan2>

Section VI: Web Addresses

Listed below are the addresses to web sites containing information on consumer direction and related topics. Each web address is followed by a description of the site including some of the information available. Many of the materials highlighted in this compendium are accessible through these sites.

Promoting Consumer Direction in Aging Services

www.consumerdirection.org

Description: The web site for the joint NASUA/NCOA project “*Promoting Consumer Direction in Aging Services*” funded by the Robert Wood Johnson Foundation, provides access to: Consumer Choice News, the project’s newsletter; the Consumer Direction Tool; and a variety of articles and publications, many of which are listed in this compendium. This site also contains direct links to other sites that provide information on consumer direction and long-term care.

Home and Community-Based Services Resource Network

www.hcbs.org

Description: The web site for the Community Living Exchange Collaborative, a joint effort of the Rutgers Center for State Health Policy (CSHP) and the Independent Living Research Utilization (ILRU), a program of the Institute for Rehabilitation and Research (TIRR). The site is designed for use by state and local administrators of home and community based services, providers, individuals with disabilities, and older persons to obtain information about long-term care service issues. The site contains a searchable database of information including policy reports and analyses, practical tools (e.g., sample budgets, assessment tools, position descriptions), legislation updates, training materials, workbooks and links to other web sites (including the CMS web site).

Information about the **Cash & Counseling Project** is available at three web sites: The University of Maryland, Center on Aging, Mathematica Policy Research, Inc., and the Cash & Counseling Web Site.

The University of Maryland, Center on Aging

www.umd.edu/aging

Description: This site contains information about the Cash & Counseling demonstration program implemented in Arkansas, Florida and New Jersey. The site provides access to a number of publications about consumer direction and links to web sites of organizations that promote the development of consumer-directed options in HCBS.

Mathematica Policy Research, Inc.

www.mathematica-mpr.com/publications

Description: This site contains evaluation reports on the Cash and Counseling demonstration projects. Persons interested in reading specific articles about the projects will need to specify “Cash and Counseling” in their search request.

Cash and Counseling

www.cashandcounseling.org

Description: *Cash and Counseling* is the web site of the national project funded by The Robert Wood Johnson Foundation, the office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services (ASPE/DHHS) and the U.S. Administration on Aging (AoA), and the Centers for Medicare and Medicaid Services (CMS). The site contains information about the Cash and Counseling Demonstration and Evaluation (CCDE) project including reports and studies of projects in Arkansas, Florida, and New Jersey, and the new grant program that will fund Cash and Counseling projects in ten new states beginning in 2004.